



# the Blood Line

## Recombinant Factor VIII Trial Programs

Several manufacturers have sample recombinant factor VIII trial programs available. If you are interested in learning more about these programs and the products available for sampling, please contact the HTC and discuss this with Karla or Tami.

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Co-Editors: Kari Atkinson & Nancy Patrilla

## Camp Superfly II News

*by Kari Atkinson*

**C**ONGRATULATIONS! Have you heard the news? The IOWA YELLOW JACKETS took 2<sup>nd</sup> place in the Camp Superfly II competition this year. That means we have another \$10,000 to use for camping experiences!!! THANK YOU TO ALL who took the time to complete and mail in the forms. Thank you to Baxter BioScience for sponsoring this program for a 2<sup>nd</sup> year.

Baxter BioScience increased the monetary prizes this year to give more chapters the opportunity to participate in order to earn money to either make improvements to an existing camp, create a new camp or to provide funding for improvements to an existing camp. This year, teams competed in one of three divisions, based on the number of individuals participating. The first place team in each of three divisions won a \$30,000 grant for summer camp, the second place teams received \$10,000, and the third place teams each won \$5,000. The 18 remaining teams who competed this year, earned an honorable mention and a grant of \$500. The total grant money distributed in 2006 was over \$140,000, nearly triple the awards given in 2005. Hemophilia of Iowa and all the future campers at Camp Tanager THANK YOU!!!

## News You Can Use

### Why Visit a Hemophilia Treatment Center?

*By Ann Dery, RN*

**S**eeking care is not everybody's idea of fun, but if you have a bleeding disorder, there are good reasons to visit a hemophilia treatment center (HTC). Since the creation of the federally-funded HTC network in 1976, studies have shown a 40% decrease in mortality for males with hemophilia who receive comprehensive care within the network. Comprehensive care is a specialized, multi-disciplinary approach to healthcare that provides treatment, evaluation and education promoting long-term health and vitality. So how do patients directly benefit from seeing the comprehensive care team at an HTC?

Due to the rarity of bleeding disorders, an HTC is one of the few places where patients can expect to find knowledgeable healthcare

professionals to treat them. If nearby, and unable to self-infuse, some patients may visit their HTC frequently to receive treatment for bleeding episodes. As they learn more about their condition and treatment over time, they may be able to make the transition to home infusion.

Others may visit an HTC when more serious, problematic bleeds do not resolve completely with the usual treatment. In this case, a person may need physical therapy, x-rays, or a change in factor dosage or frequency of infusions. All of this can be done after an evaluation by a physician and nurse at an HTC.

The most common reason that patients visit an HTC is for a comprehensive annual exam. The annual exam is a key component of comprehensive care, especially for patients with severe or moderate forms of bleeding disorders. (Those who are mild should be seen at least every two years.) During a comprehensive exam, patients will usually see a hematologist, nurse, social worker, orthopedic physician and physical therapist. They may also see a nutritionist, geneticist, psychologist and/or dental hygienist, depending on the circumstances. The comprehensive care team will typically cover the following topics with the patient:

Bleeding/infusion logs – Reviewed to determine the effectiveness of the current treatment regimen and to identify the emergence of a "target"

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area (logs should be mailed in advance to the nurse coordinator or brought to the visit for review).

Factor prescription – Reviewed for a possible change in dose based on the patient's weight and frequency of bleeds.

Joints and muscles – Evaluated for function, tightness and weakness.

Psychosocial concerns (e.g., finances, child care, insurance, relationships, school, work) – Addressed as needed.

Immunizations – Given as needed to stay up to date.

Blood work – Tested as needed.

Dental check-ups – Scheduled/ conducted as needed.

Aside from receiving treatments and being evaluated, an HTC is ultimately a place for patients to get their questions answered. By learning about their bleeding disorder, treatments and therapies, and inquiring about their homecare options, patients will discover that the world of bleeding disorders may be more manageable than they believed. In the end, a knowledgeable patient is a healthier patient.

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**Treat Early, Treat Early, Treat Early.**

By Ann Dery, RN

**H**ow many times have you heard how important it is to treat a bleed early? The truth is we can't hear that message enough. Simply put, treating a bleeding episode early limits the amount of blood that can cause damage to joints and muscles.

In people with bleeding disorders, the most common bleeds occur in joints and muscles. In joints, a build-up of blood breaks down the synovial membrane and cartilage that protect them. Deterioration of these protective tissues can lead to more frequent bleeding, permanent joint damage, and limitations of mobility. In muscles, bleeds heal with scar tissue that is not as flexible as normal muscles, leading to an increased risk of bleeding. With

major or repeated bleeding, muscles weaken. Deep muscle bleeds also threaten damage to nerves and blood vessels, making early treatment a key to avoiding serious health risks.

Treating bleeds early has both immediate and long-term benefits:

- **Reduced risk of future bleeding.**
- **Prevention and/or delay of joint and muscle problems (e.g., arthritis, range of motion limitations).**
- **Speedy recovery and return to normal activities.**
- **Prevention of muscle weakness.**
- **Reduced pain and discomfort in the area of the bleed.**
- **Prevention of a target joint\* development.**
- **Delaying treatment of bleeds has both immediate and long-term consequences:**
- **Increased risk of future bleeding.**
- **Increased swelling of joints and muscles, and the likelihood**

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— John Kowalski, 21  
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of long-term joint and muscle problems.

- Delayed return to normal activities.
- Weakened muscles.
- Intensified and prolonged pain to the affected area.
- Increased risk of target joint\* development.

\*A target joint is one that experiences recurring bleeds (4 or more in 6 months or at least 20 in a lifetime), increasing the risk of permanent damage.

Ann Dery is a bleeding disorders Clinical Nurse Specialist for Coram Hemophilia Services. She has 30 years experience as a practicing nurse, including 18 as a hemophilia treatment center nurse clinician caring for adult and pediatric patients.

To detect a joint or muscle bleed, look for these warning signs:

- Reduced mobility, or favoring a particular arm or leg.
- Swelling or redness
- Warmth at the site of the bleed.
- Bubbling or tingling sensation.
- In babies, unusual crying and/or fussiness.
- In toddlers, crawling instead of walking.

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**Novel Gene Therapy May Lead to Cure in Hemophilia A Patients (Even Hard to Treat Subset Requiring Expensive Treatment)**

Discovery by Medical College of Wisconsin and BloodCenter of Wisconsin researchers in Milwaukee may be a key to a permanent genetic cure for hemophilia A patients, including a subset who do not respond to conventional blood transfusions. The study of genetically altered hemophilia mice is published in the July 2006 edition of The Journal

of Clinical Investigation.

Hemophilia A affects about one in 5,000 males who lack the hereditary blood clotting protein, Factor VIII (FVIII). Traditional treatment requires infusion of synthetic FVIII two to three times a week to control bleeding episodes. However, about 30 percent of these patients develop antibodies to FVIII, selectively inactivating its clotting properties and negating its therapeutic role. Treatment for adults who have these inhibitory antibodies can cost over \$1 million annually if there is a major bleeding episode.

"We developed a Trojan horse approach cloaking FVIII in a platelet so that it is undetected by the antibodies and its clotting properties are preserved until the platelet sticks to a damaged blood vessel

and releases its stored protein which now includes FVIII," explains senior author Robert R. Montgomery, M.D., senior investigator at the BloodCenter of Wisconsin and professor of pediatric hematology at the Medical College. He is also affiliated with the Children's Research Institute.

"This is truly a landmark development for hemophilia A patients," says hematologist, Joan Gill, M.D., professor of pediatric hematology at the Medical College, and director of the Comprehensive Center for Bleeding Disorders at the BloodCenter and Children's Hospital of Wisconsin. "We look forward to the day when basic research is completed and clinical trials can begin in patients."

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circulating in plasma (the liquid portion of the blood) stick to the site of the blood vessel wound, activate its surface and rapidly stop the bleeding. In hemophilia patients, infusion of FVIII replaces the missing clotting factor and enables normal cessation of bleeding. However, some 30 percent of patients see the FVIII as a foreign protein and mount antibodies to destroy it, rendering the FVIII treatment useless.

Newer FVIII treatment products that bypass this attack can run into \$10,000 or \$100,000 per treatment episode and costs for a patient may exceed \$1 million annually. So far, attempts at gene therapy for a permanent cure have not been successful.

According to the lead author, Qizhen Shi, M.D., Ph.D., an American Heart Association supported postdoctoral fellow, "Our team of scientists have developed an approach in mice that not only could make gene therapy successful for patients with hemophilia who don't have antibodies, but more importantly can be used to treat

patients with antibodies.

"To get around the antibody attack on FVIII which occurs readily in plasma, we inserted a gene into a blood stem cell so that FVIII is produced and stored in blood platelets, hidden from view and attack, ready to release when a blood vessel is damaged, quickly enabling normal clotting before the antibodies can begin their attack. Our approach was very effective even in mice treated with five to ten thousand times the amount of antibody that would normally prevent treatment of a hemophilia patient with FVIII."

The new method will next be tested in larger animal models before clinical trials can begin in patients. Blood and bone marrow stem cells would be harvested from hemophilia patients in much the same way they are collected from bone marrow donors. A non-replicative virus containing the FVIII gene would be introduced into the stem cells from the patient. The FVIII engineered for production only in platelets would insert itself into the DNA of the stem cells. These same

stem cells would then be given back to the donor patient and the stem cells would continue to make blood cells normally, releasing the life-saving FVIII only when the platelets stick to a bleeding site of injury.

"This process would last for the rest of the patient's life and will work regardless of whether antibodies are present or absent," says Dr. Montgomery. "There will be many more studies needed to apply this approach in patients but this treatment could normalize bleeding for patients with hemophilia.

"What is most exciting about this first design of gene therapy for hemophilia is that it works not only for routine hemophilia but also for the 30 percent of patients who have developed inhibitory antibodies that make normal replacement treatment impossible," Dr. Montgomery concludes.

The study is funded by the National Institutes of Health. Other researchers include David A. Wilcox, Ph.D., associate professor of pediatrics;

Hartmut Weiler, Ph.D., assistant professor of physiology; Clive W. Wells, electron microscopy specialist; Brian C. Cooley, Ph.D., associate professor of orthopaedic surgery; and Jack Gorski, Ph.D., senior investigator at the Blood Research Institute.

Link to source: [http://www.eurekalert.org/pub\\_releases/2006-07/mcow-ngt062906.php](http://www.eurekalert.org/pub_releases/2006-07/mcow-ngt062906.php)

### **Factor Quest Meets Education Need**

According to a recent focus group, a key need in the bleeding disorders community is an effective way to teach kids about their condition – one that improves retention and makes learning fun. Coram Hemophilia Services has accomplished exactly that with the creation of the internet video game, *Factor Quest*. By incorporating real-world lessons into a fun-filled fantasy adventure, *Factor Quest* offers an experiential way for kids to learn

basic concepts about managing their bleeding disorders. From learning to drive to learning to infuse, experience can often be the best teacher.

The test version of *Factor Quest*, called *Cavern of Bones*, was recently unveiled at the National Hemophilia Foundation (NHF) meeting in San Diego. In the *Cavern of Bones*, players are trapped inside a volcanic cave representing the inside of a bleeding joint. As the character Hemo-Phil-a-Saurus™, players are challenged to extinguish the boiling lava entering the cave and search for the four keys to long-term joint health. To master the challenge, players must find and infuse clotting factor to avoid damage from the lava bubbles. They can also learn the lifesaving value of a medical identification bracelet without the life-threatening experience.

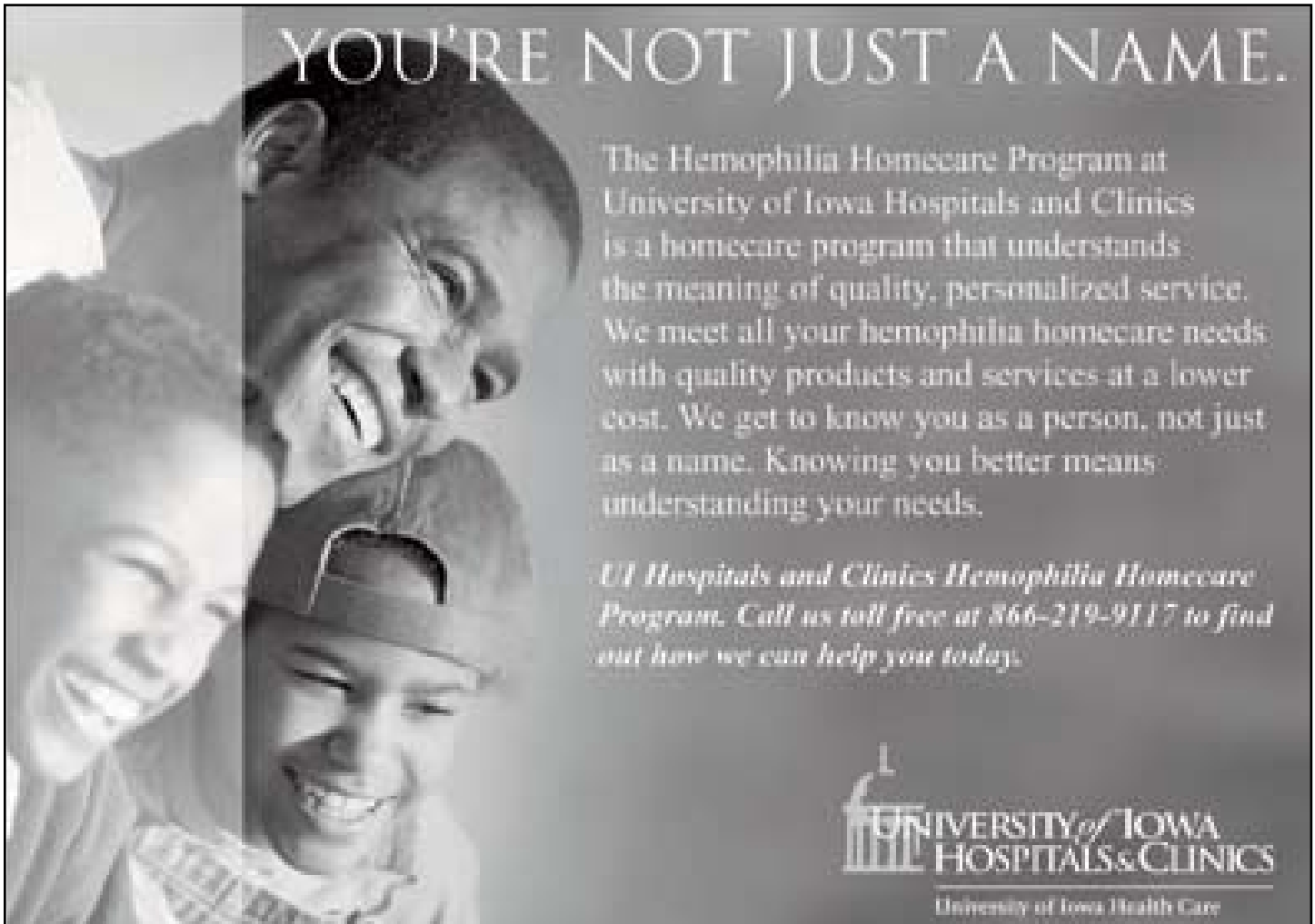
One hundred percent of players surveyed at the NHF meeting said they enjoyed playing *Factor Quest* very much and would play again. To gather

more experience and feedback on the game, Coram Hemophilia Services has posted the test version of the game online at [www.coramhemophilia.com](http://www.coramhemophilia.com). Players can send their feedback directly to Coram Hemophilia Services by emailing [factorquest@coramhemophilia.com](mailto:factorquest@coramhemophilia.com). To play the game, Macromedia Flash Player must be installed on your computer. A free copy of the player can be downloaded at [www.macromedia.com/downloads](http://www.macromedia.com/downloads). Enjoy!

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### **First Generic HIV/AIDS Drug Approved**

The Food and Drug Administration issued the first generic approval for a capsule dosage of zidovudine to treat HIV/AIDS to be marketed in the



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U.S. The approval will help reduce the cost of this therapy for American patients.

The tablet and oral solution dosage forms of zidovudine were previously approved for sale in the U.S. under the trade name Retrovir®. GlaxoSmithKline’s patent on its capsule form of the product expired in September 2005, allowing the development of a generic version.

Zidovudine is a nucleoside reverse transcriptase inhibitor which helps keep the AIDS virus from reproducing. It is used with other anti-retroviral agents for the treatment of HIV-1 infection.

*FDA press release, March 31, 2006*

## Condolences

We were saddened to recently learn of **Darlene Kanfield’s** death. As you may remember, Darlene was one of our board members. She gave generously of her time to be part of the Hemophilia of Iowa Board of Directors. What made her service unique was that Darlene supported our efforts even though she did not have a family member with a bleeding disorder. Her friend, Cathy, has a son with a bleeding disorder; so Darlene decided to become involved with

Hemophilia of Iowa so she could be part of a strong support system for Cathy. Our sincere sympathy goes to the family and friends of Darlene Kanfield.

We also want to offer our sincere sympathy to the family of David Postal, who recently passed away.

## Athletic News

### High School:

Congratulations to **Dylan Humburg, son of Keith & Dawn Humburg**, for advancing with his high school track team to both the Drake Relays and the State track meet. Dylan recently shared some of his thoughts with us on this exciting season:

My track season as a sophomore started in late March here at Humboldt High School. My coaches told me that they had high expectations for me and that I would be a big part of our varsity team this year. I quickly found out that I had gotten a lot faster since my freshman year, and I could keep up with the much older guys. I found myself running many different things, such as the open 200, the 4x100, the 4x200, the 4x400, the 1600 medley relay as well as the long jump.

As the track season went on, my track coach told me that I could have a chance at qualifying for the Drake Relays. He told me that in order for

me to qualify I needed to get into the top 60 of any of my events. He told me this *one* meet before the Drake Relays so I knew that I had to try really hard at my next meet, which was at Forest City.

I was in the top 70 to the top 100 in all of them except for my 4x100 team. That night at Forest City, my 4x100 team and I ran very well and clocked a time of 44.91 seconds. That was our fastest time of the season, and we found out the next morning that we had qualified for the Drake Relays with our 4x100 relay!

At first, I had no idea how big the Drake Relays were. However, I soon found out that this track meet was a very big deal. My team and I drove to Des Moines on the Friday of the relays. We relaxed in our hotel rooms until it was time for us to run. Finally, the time came to run and I got nervous—really fast. We arrived at the stadium about two hours before our race. For those two hours I did nothing but stretch, run, and practice handoffs. When it came time to go check in at the track, I began to get very nervous. We checked in and soon enough my time came to race. I took off my sweats and headed down the track to my starting position. It was very cold and rainy that day. I found myself gazing in awe at the 10,000 plus screaming and yelling fans

Finally I got to my lane. We received Lane 1, which is not a very good lane to have; and I marked off my usual 17 steps from the start of my exchange zone. I then marked this with a piece of tape. Finally the race started; I ran the second leg of the race. My teammate came flying in, gave me the baton, and I took off as fast as I could. Then I gave the baton to my teammate and watched him run around the corner. Finally, the last exchange, and my teammate handed it off to the last man. He sprinted toward the finish line where we finished third in our heat. I was so relieved that we had clean handoffs. We ended up finishing 42<sup>nd</sup> out of 60.

After Drake, my track season went on until Districts at the end. You have to get 3<sup>rd</sup> or better at Districts to advance to State. Once again, on the day of Districts, it was very cold and cloudy. Not really ideal running

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Pictured: Kyle Callahan,  
HHS Client and President,  
with Bea Grimes, Nurse Case Manager

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weather. My first event of the night was long jump. I did my first two jumps and found myself in 4<sup>th</sup> place; I jumped one last time and missed 3<sup>rd</sup> place by only 1 inch. That was kind of disappointing. My next event was the 4x200 meter relay. I ran the second leg. Once again my teammates and I came up short. We got 4<sup>th</sup> place by about 2 feet. My next event was the 1600 meter medley relay. I also ran the second leg of that and, once again, we came up short with a 4<sup>th</sup> place finish. So far I had three 4<sup>th</sup> place finishes. My last race came around, which was the 4x100 meter relay. I was hoping that we could squeeze out a 3<sup>rd</sup> place victory so my teammates and I could advance to State. We ended up getting 3<sup>rd</sup> so, yes, indeed, I had made it to State. I felt relieved now because I had gotten three 4<sup>th</sup> place finishes but needed a 3<sup>rd</sup> or better finish to advance to State. My team ended up winning the District title and advancing in 13 out of 16 events. State was held at Drake, and most of my team went to Des Moines to race.

We went down on Friday but I didn't have to run until Saturday so I had a

day to relax. Saturday was a very hot and sunny day-very nice weather to run in. I began warming up with my teammates about two hours before our race. This time when I stepped on the track getting ready to run, I didn't feel as nervous; but it was still very exciting. Once again, as I had done

the month before, I got in my lane, marked off my 17 steps and got ready to run. This time my team ran a much better time. I think we placed in the top 20 of Class 3A.

Being a hemophiliac has definitely made my life different from other people. I have seen many other kids



with hemophilia who have much more severe problems than mine. It makes me thankful that I am able to be really good at something like track when I know that many kids with hemophilia are unable to be good at something like that. Not because of their ability to be good at it but because the condition that we share often holds us back from being good at sports or anything else. It makes me very proud to be able to do this and to be able to show that kids with hemophilia can be good at sports or anything they want to—that hemophilia is not a disadvantage in life.

#### College:

**M**att Patrilla traveled to the UCLA campus in late spring to participate in the United States Intercollegiate Archery Championships, where he placed in the top 20 in the nation. The division Matt shoots in is called Olympic Recurve. The archers shoot four different distances, over the course of two days,—from 90 meters (length of a football field) to 30 meters. He shot for the Kirkwood Community College team. This trip capped a year of traveling to Georgia College & State

University (Milledgeville, Georgia), Michigan State (East Lansing, Michigan), and Case Western Reserve University (Cleveland, Ohio) as well as shooting in the Iowa Games and at various State meets. Currently, Matt is organizing an archery club at Iowa State University (as a club sport, members pay their own expenses for various meets...).

#### 2006 Dude Cremer Memorial Golf Tournament

**T**hank you to everyone who participated in the 2006 Dude Cremer Memorial Golf Tournament. The golf tournament was held at Bos Landing Golf Resort in Pella. The chatter after the event was that it was a beautiful course and a great challenge. A huge thank you goes to Bill Laughlin for chairing the event. He did an incredible job seeking sponsorships, finding the wonderful golf course and, of course, organizing all of the golfers. We had a total of 19 golf teams participate. Congratulation goes to Dr. Lentz's team for winning the tournament.

This event would not have been possible without our sponsors. A special thank you goes to ARJ Infusion Services, Baxter BioScience, Bayer Healthcare, Bio Rx, Hemophilia Health Services, Midwest Cornerstone, University of Iowa Home Care, Wyeth, ZLB Behring, Iowa Health Systems, Ottumwa Shrine Club, Acute Care Inc., Hemophilia Options, Ideal Ready Mix Co, Iowa Kidney Stone Center, Dr. Steven Lentz, and Schmidt Family Funeral Home. A huge thank you also goes to all of the people who volunteered the day of the event. Their many duties consisted of registration, silent auction, raffle, and sitting at each hole where there was a contest.

Please watch your mail for a "Save the Date" postcard for the 2007 Dude Cremer Memorial Golf Tournament. Hope to see you there!

#### Scholarship Thank You

*By Andy Meyer and Ben Meyer*

**W**e would like to thank you for the two scholarships that we have received. Ben will use his

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scholarship at Iowa State where he will be entering his sophomore year majoring in Industrial Technology. Andy will use his at UNI where he is currently enrolled as a 5th year senior majoring in Biology Education. This will be his final year of college. He plans on graduating from UNI in December. We also would like to thank Hemophilia of Iowa for all the assistance that you have given us through the years. We would not be where we are without the help of such a generous organization. Again, thanks for the scholarships.

### **Thank You**

*By Matt Patrilla*

I would like to thank you for the Hemophilia of Iowa Scholarship.

When it comes time to pay the school bill each semester, it is always a rude awakening. The scholarship has helped a great deal in diffusing the cost of tuition this semester here at Iowa State University, and for that I thank you.

*By JoDee Edmonds*

**I**n this installment, we'll look at how hemophilia introduced itself into the royal families of Spain and Germany (Prussia).

When we last read about Queen Victoria of England, she had lost her son, Leopold, to a brain hemorrhage at age 31. He left behind a German wife, Helen of Waldeck, and a daughter, Alice. Alice married and her son, Rupert, had hemophilia. Rupert died at age 21 as a result of a brain hemorrhage. But Victoria, if you will remember, also had daughters, two of whom (Beatrice and Alice) were carriers of the hemophilia gene. The older of the two, Alice, married and had six children, three of whom were afflicted with hemophilia. One of her sons, Frederick, died at age three from internal bleeding after falling through an open window.

Victoria's younger daughter, Beatrice, married and had two sons, Leopold and Maurice, who were both hemophiliacs. Her daughter, Victoria-Eugenie, was a carrier. Victoria-

Eugenie married Alfonso XIII, the King of Spain. They had six children. The first, Alfonso, had hemophilia, as did the fourth, Gonzalo. The other sons and daughter were unaffected.

One of Alice's daughters, Irene, who was a carrier, married her first cousin, Prince Henry of Prussia. It was common back then for first cousins in royal families to marry. They though it kept the bloodline pure. Her two sons were hemophiliacs. The youngest, Waldemar, bled to death at age four. His brother, Henry, died at age 56.

Next time, we'll look at how hemophilia came into the Russian Imperial Family and how that changed the country's history.

## **Interesting News**

**T**he National Hemophilia Foundation and the Centers for Disease Control and Prevention conducted a national survey focusing on knowledge about, attitudes toward, and behaviors associated with key prevention activities among youths with hemophilia and used the data gathered to design a health promotion campaign.

*Methods:* A national, random sample of 459 patients was drawn from 20 hemophilia treatment centers and 8 hemophilia associations; 110 (24%) of the respondents were young people. A telephone questionnaire was used to measure knowledge, behaviors, and barriers to prevention.

*Results:* Thirty-six percent of the youth respondents believed that joint disease cannot be prevented; 60% managed hemophilia by avoiding physical activity. Only 31% of the respondents treated bleeding episodes within 1 hour. Although hepatitis was a clear threat to this hemophilic cohort, 78% did not know transmission routes for hepatitis C, and 67% did not know transmission routes for hepatitis B.

*Conclusions:* Young people with chronic disorders need help

understanding that they can prevent complications. We identified key messages for a hemophilia prevention campaign, including exercising to ensure healthy joints and treating bleeding episodes early and adequately. (*Am J Public Health*. 2006;96:XXX-XXX. doi:10.2105/AJPH.2005.075234)

A complete version of this study can be read at the following website: <http://www.ajph.org/cgi/doi/10.2105/AJPH.2005.07523>

By: Kari Atkinson

The First Step parent coordinators would like to express their sincere gratitude to the industry and individuals who have contributed to our First Step program through the industry and individual sponsorship program. The levels that have been



designated are listed below. The 2005-2006 sponsorships we have received specifically for the First Step program are listed below next to the level of their gift. A HUGE THANK YOU TO THOSE WHO HAVE CONTRIBUTED!

**Platinum**(\$1,000 & above): BioRx

The Employees of AEGON USA's Fundraiser

**Gold**(\$750-\$999):

McCarthy Family Fundraiser

Baxter BioScience

**Silver**(\$500-\$749):

ARJ Infusion Services

**Bronze**(\$100-\$499)

**Diamond**(up to \$99)

Upcoming events for the First Step

program:

**October 3** - "Navigating the ER" in Waterloo

**February 17-** Family Education/Fun weekend in Burlington at One Fun City

If you have questions about First Step, please contact one of the parent coordinators:

Jill Nolte @ 319-213-1009 or [jnnolte@gmail.com](mailto:jnnolte@gmail.com);

Kari Atkinson @ 319-438-1249 [caklatkinson@aol.com](mailto:caklatkinson@aol.com);

Mary McCarthy @ 641-658-2783 [hemophiliaofiowa@yahoo.com](mailto:hemophiliaofiowa@yahoo.com)

We have worked hard trying to get this program up and running, and we have appreciated every dollar received.

If you have not had the opportunity to provide a sponsorship and would like to become a First Step contributor, we would love to hear from you. You can contribute by sending your donation specifically marked for First Step to the Hemophilia of Iowa Treasurer, Dawn Humburg, 1002 6<sup>th</sup> Ave SW, Humboldt, IA 50548.

## Family Camp Recap

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[www.zlbbehring.com](http://www.zlbbehring.com) ID#102-11461C 11/2005

By: Kari Atkinson

The first Hemophilia of Iowa family camp was held on August 12 & 13 at Camp Tanager. Six families attended, and it was a remarkable experience for all of us. Without the Camp Superfly grant, this would not have been possible. Thank you, Baxter BioScience!

The weekend was filled with several fun events—crazy games that we all probably played as kids. In one game, we ran down to a baseball bat, spun around it three times while keeping our foreheads touching the bat and then attempting to “run” back to the starting line. I don’t think too many were running straight after that one! I think the one the kids liked the best was one parent from each family had to lay on the ground about 50 feet out and hold a cup on their forehead. Then bowls of water were given to each team and the object was to see which group could get the most water in their team’s glass carrying it with a tablespoon. Well, needless to say, Sherri and my team did not



have a very good aim and most of the water ended up on us instead of in the cup. Brian and Tom’s teams appeared to be a little nicer to them because they did not seem as wet as we did. After the games, the kids and adults loved the awesome pool time at Camp Tanager. Once pool time came to an end, dinner was served. The food was very excellent, and the cheesecake topped with strawberries made your mouth

water! The kids then enjoyed a circus-themed carnival with games for all ages. “Dirt and worms” were then made by the campers while the parents enjoyed a wonderful session of massage therapy. It was soooo relaxing that some of us just about fell asleep. At the end of the evening, we all enjoyed the bonfire and singing campfire songs led by the Camp staff. With the bugs

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\*As compared to the original BAXJECT and needles.

Reference: 1. Data on file, Wendake Village, Calif. Baxter Healthcare Corporation.  
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**Baxter**



coming out and the kids exhausted from the busy day's activities, some turned in for the night but others took advantage of the childcare offered by Tami Bullock and the camp counselors. The parents then enjoyed watching the video from Hemophilia summer camp, conversation, and snacks before we all turned in.

On Sunday we were blessed with another gorgeous day. The day started with breakfast, and then we took off on a family scavenger hunt. This gave each family the opportunity to see more of Camp Tanager and to get to know the camp counselors. They truly do have huge hearts. Did any of you know that most of the camps are with children that have behavior disorders? The counselors are incredible people! Some of them were a little down because they had spent the entire summer together, and this was their final weekend. The day ended with another pool party, lunch, and then it was time to say good bye. It was really nice

to see some of our new friends that we usually only get to see a couple of times a year as well as meet new ones. I think I can truly speak for each family when I say that we can't wait for next year's camp. We will have to put a bug in someone's ear about possibly starting it Friday night!!!!

A special thank you goes to Tami Bullock for all of her hard work on the Camp Superfly competition and for planning this event. We also

want to thank Flipper for planning all the crazy events that managed to keep us busy, and the Camp Tanager staff for spending another weekend at camp and giving our children priceless memories. They put an amazing weekend together, and there was fun for every age present. Again, we want to thank Baxter for allowing Iowa to participate in the Camp Superfly event and for all of the people in the community that turned in Camp Superfly mailings.



Little Mr. Truman summed it up by saying this was MY CAMP. Truman, I think all of your new friends would agree with you!!

### **A Fun Day of Pampering**

*By Nancy Patrilla*

As I sit here typing, I am enjoying looking at my nicely groomed fingernails. It is just one of the ways that we were pampered on Saturday, September 9, by NuFACTOR here in the Cedar Rapids area. A few weeks ago, invitations were sent out on behalf of NuFACTOR to the moms giving us the opportunity to be “fussed” over.

We all know how difficult it is to take care of a child or children with bleeding disorders. We will do anything to help the health of our children—usually at the risk of not taking care of ourselves. Whether it be not taking the time to exercise, to spent time alone or just being a little indulgent to ourselves once in awhile, we simply put others first. So, Shirley and Leigh with NuFACTOR and First Step Coordinator Kari Atkinson treated us to a day just for moms.

I have to tell you, it was great! If you have the opportunity to do this in the future, please consider signing up. We met at Capri Beauty College where we were ushered into a room that had been reserved just for our use. There were tables set up and each spot had a student waiting to do a hand massage and manicure. After being welcomed by our hostesses, Kari gave a short talk on what bleeding disorders were. She then invited questions from anyone, including the students. The students were really interested in what we had to say about bleeding disorders so this was an educational time for them as well. Since the manicure spots were set up in tables for two, it was a great chance to reconnect with old friends and make some new ones. We had a total of eight moms plus Shirley and Leigh, who also have

personal experience with hemophilia. There was sparkling grape juice, hors-d’oeuvres, and mini cheesecakes to snack on while we waited for our nails to dry. We then were given fancy little goody bags with chocolates, foot cream, and handmade soap in them. After that, we headed to Zio Johnno’s for lunch. We probably spent two hours just talking and eating—and I left earlier than most!

Thank you, Shirley, Leigh, and Kari!

### **Novo Nordisk to Host Two More Inhibitor Summits**

Novo Nordisk will host two more Inhibitor Patient Education Summit meetings. The dates and locations are:

September 22-23 in Baltimore, Maryland

October 27-28 in Chicago, Illinois  
The meetings will provide learning and networking opportunities for the inhibitor community. The agendas were developed by national and local hemophilia leaders. Some of the topics addressed include treatment strategies, Immune Tolerance Therapy, exercise and sports, joint health, and insurance changes and challenges.

Travel grants will be available to eligible individuals and administered by the National Hemophilia Foundation and Hemophilia Federation of America chapters. For more information or to pre-register, please visit [www.inhibitorsummits.org](http://www.inhibitorsummits.org) or call toll free at 1-888-706-6867.

### **2006 Annual NHF Meeting**

The National Hemophilia Foundation is hosting its 58th Annual Meeting in Philadelphia, PA, from October 12 - 14, 2006.

The registration deadline was **August 31, 2006. However, if you are interested in attending but you did not pre-register, call the NHF Meeting’s Department at 800-424-3634, ext 4, to see if it is still possible to attend.**

## **And Finally**

*By Nancy Patrilla*

If you have any news you would like to share, please contact us at [hoi\\_bloodline@yahoo.com](mailto:hoi_bloodline@yahoo.com).

HAVE YOU CHECKED OUT OUR NEW WEBSITE? Special thanks go to Tom Recker for making this possible. Please go to [www.hemophiliaofiowa.com](http://www.hemophiliaofiowa.com) and explore. If you have any comments on the newly designed website, Tom would welcome the feedback.

Not too long ago, I read about a conversation between some mothers of young hemophilic boys. I won’t even try to quote the exact conversation but I believe that the gist of it was that they had apparently observed a young adult with hemophilia. They were concerned because the young man had a “bad” ankle. They thought that it was terrible that he had to deal with a joint that had been harmed due to bleeds. How far we have come! Almost that same conversation, in reverse, took place between J.J. Goedken and John Heisner at one of our very first “annual” meetings. We had a young man in his early thirties in to speak with our group and he had a “bad” ankle. J.J. and John couldn’t believe that all he had was a “bad” ankle. In J.J. and John’s era, people with hemophilia experienced crippling in many of their joints, and it was considered normal. I think it is a wonderful testament to our Hemophilia Treatment Centers, the great caregivers, and pharmaceutical advancements that it is now considered an unusual event to have a “bad” joint!

Dear Hemophilia of Iowa Member:

Are you interested in becoming a consumer board member of Hemophilia of Iowa? If you are a 2006 member of Hemophilia of Iowa, not working for a bleeding disorder company and willing to volunteer your time, we want to hear from YOU!!! The Hemophilia of Iowa annual meeting is fast approaching. Enclosed is a brochure which explains in detail about the Hemophilia of Iowa Annual Education Weekend held on October 28 – 29 at the West Des Moines Marriott.

The annual meeting will include an election for new Board members. Hemophilia of Iowa currently has 5 seats open on the board. All board seats are for a 3-year term. Board Member responsibility includes attending approximately six (6) meetings per year (in person); this meeting is usually held in the Des Moines area on Saturday mornings. Occasionally there are Board member conference calls held in the evenings. You will be reimbursed for mileage to and from meetings and events. You will have the opportunity to help Hemophilia of Iowa better serve the bleeding disorder community in Iowa. Board members are also asked to actively participate in committees, which support events, fund-raising and communication to the bleeding disorder community. Elected board members will be announced during the evening festivities. Please note that if you are voted in as a Hemophilia of Iowa board member, there will be a board meeting on Sunday, October 29, at 11 am. It will be over at approximately 1 p.m.

If you are interested in running for a seat on the board, please send or e-mail a letter with your offer to run for the board answering the following questions along with a photo of yourself (a photo is preferred but not mandatory). Please answer with maximum of 2-3 sentences for each question.

What is your relationship to the bleeding disorder community?

What kind of experience do you have to bring to the chapter?

Which part of the chapter committees would you be most interested in helping with? The chapter committees are listed below.

Anything else you would like to share about yourself and your desire to join our board.

We will compile the prospective board members' answers on an information sheet to give to all voting members at the meeting.

If you have any questions, please contact one of the members of the membership committee listed below. Please return your Board Question Answers to Kari Atkinson at PO Box 415, Central City, IA 52214 or via e-mail at [caklatkinson@aol.com](mailto:caklatkinson@aol.com). Please respond by October 20, 2006.

Committees are as follows:

Membership  
Annual Meeting  
Information  
Camp Superfly  
Bylaws  
Fundraising  
Scholarship  
Support Group  
Medical Advisory  
Public Relations

Kari Atkinson  
319-721-3964  
[caklatkinson@aol.com](mailto:caklatkinson@aol.com)

Dawn Humburg  
515-332-5069  
[humbug5@mchsi.com](mailto:humbug5@mchsi.com)

Cathy Treichel  
319-358-9868  
[meow1ct@aol.com](mailto:meow1ct@aol.com)

### Education Meeting

October 28th & 29th, 2006  
West Des Moines, Iowa

#### West Des Moines Marriott Highlights

All guest rooms feature complimentary high-speed Internet access, 2-line phones, voice mail and complimentary coffee, to keep you productive. Relax in the whirlpool and sauna or work out in the fitness center or indoor 20-yard pool. Casual dining is convenient all day long at CK's Steakhouse, or enjoy lunch and dinner at Fountains Lounge.

- Located in West Des Moines, 15 minutes from Des Moines Int'l Airport on complimentary shuttle
- Off I-80W at Jordan Creek Pkwy, near Jordan Creek Town Center and Iowa's best shopping and dining
- The Room That Works® guest rooms with large, well-lit work desk and ergonomic chair
- Complimentary in-room coffee and tea service
- The new bed from Marriott -- down comforters, designer duvets, fluffier pillows
- Complimentary turndown service daily

The planning committee would like to invite you to participate in our upcoming meeting, held on October 28 and 29th in West Des Moines. The Marriott is a beautiful hotel with a great pool and gorgeous rooms. A perfect facility for enjoying time with family and fellow Hemophilia of Iowa community members, while being provided education on new approaches to living full, active, healthy and independent lives.

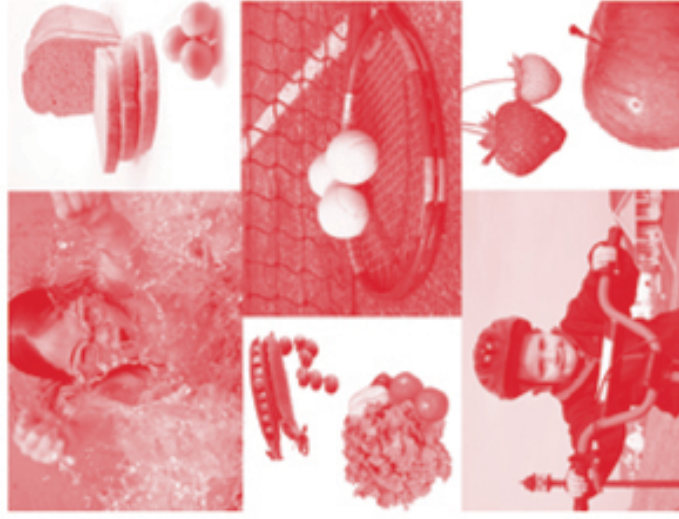
We are grateful for the input of the committee and the University of Iowa HTC for identifying programs that would be most beneficial to the community.

Through out the day on Saturday, many vendors will be joining us to share the latest developments and services available through our industry members. Starting at 5pm on Saturday, we have reserved time to enjoy the pool and camaraderie with food and refreshments nearby. The evening brings dinner, the announcement of our newest Board Members and a celebration of our Camp SuperFly 2nd place finish and \$10,000 grant. This will be followed by a DJ and costume contest. All are invited to dress up!

Childcare will be provided from 10:30-3 pm on Saturday.

The accompanying agenda will give you all the details you need to learn more about the events throughout the day. Please review and register for the weekend by October 7th, 2006. We look forward to your involvement in this great weekend ahead!

Peggy Wier and Bill Laughlin  
Hemophilia of Iowa Board Members  
Annual Education Meeting Co-Chairs



With a special focus on transitions for adolescents, increased knowledge for younger children and balancing nutrition and exercise for a healthy lifestyle

#### West Des Moines Marriott



West Des Moines Marriott®

1250 Jordan Creek Parkway

West Des Moines, Iowa 50266 USA

Phone: 1-515-267-1500

Fax: 1-515-223-1687

### Event Schedule

#### Saturday, October 24, 2006

**8:30 - 10:30 am** Register and visit the vendor booths. Board Member Candidate information and voting ballot for Hemophilia of Iowa members will be provided at check-in. Enjoy food and beverages in the exhibit area.

#### 10:30 - 11:30 am Mission Transition

*Sponsored by Hemophilia Options*  
Interactive sessions for children ages 6-11, broken into age groups based on specific areas of interest, including for the younger children, black light hand washing and inclusion practice with Chester chest. Older children will experience mock pharmacy calls, information on college life and vocational training and social challenges.

#### 11:30 am - 1:00 pm Lunch

A formal welcome to the annual education weekend! Overview of the activities and goals of Hemophilia of Iowa. Introduction of current board members and board candidates.

#### 1:00 - 2:30 pm

*Key Note Speakers*  
*Sponsored by Bauer BioScience*  
**Nutrition for Exercise and Sports**  
Presented by Brittan Browning, MS, RD, Children's Memorial Hospital, Chicago, IL  
**Balancing your Exercise Routine**  
Presented by Jeffrey Kallberg, PT

#### 2:30 - 3:00 pm Break

Visit vendor exhibits and enjoy a mid-afternoon snack. Check in to rooms.

#### Concurrent Sessions:

##### 3:00 pm Aspen Athletic Club

Bus leaves for Aspen Athletic Club on Hickman Road (4.13 miles away) Personal trainers will work with children and parents in a station format, introducing the life-long benefits of safe exercise using various physical fitness equipment and other exercise activities such as tennis, cardio workouts, Tai-Kwon-Do, kicking, and resistance training that can be enjoyed at home or at many school gyms. Children under 12 need to be accompanied by an adult at the Aspen Athletic Club. The bus will return to the hotel at 5 pm.

##### 3:00 - 5:00 pm BioBuddies

*Sponsored by BioBCT*  
For children between 3-10 years old, participants will enjoy an interactive, hands-on approach to learn more about their own particular bleeding disorder (or their siblings) Puppets, games, puzzles and other activities are set up in stations around the room. BioBuddies will also give children the opportunity to discover new ideas while learning about the infusion process.

#### 3:00 - 5:00 pm

**First Step Rap Session**  
for parents who do not attend the health club and may have children in the BioBuddies Program. Designed to be a "Parent Information Exchange".

#### 5:00 - 6:30 pm

**Swimming at the pool**  
or a family break. Appottizers and refreshments will be available in the courtyard outside of the pool.

#### 6:30 pm

**Dinner**  
Announcement of new Board Members, Camp Soperffy II 2nd Place Finish Celebration and check presentation, Vendor recognition and raffish

#### 8:00 pm

**Dance with a DJ** and a Halloween costume contest—all ages are invited to dress up!

### Event Schedule

#### Sunday, October 29, 2006

#### 9:00 - 9:45 am

**Buffet Breakfast**

#### 9:45 - 10:30 am

**Presentation**  
by Mike Lammner USM and Joel Lee PT regarding the grant for the Iowa Fitness Initiative.

#### 10:30 am

**Annual Education Meeting**  
Adjourned

#### 11:00 - 1 pm

**Board Meeting**  
Includes newly elected board members and voting of executive officers for the upcoming 2006/2007 term.

Be sure to check out our new website!  
[www.hemophilialiaoflowa.com](http://www.hemophilialiaoflowa.com)

**Hemophilia of Iowa Annual Education Weekend Registration Form---Registration Deadline: October 7, 2006**

Please indicate enclosed registration fee: \_\_\_\_\_ \$15.00 per person \_\_\_\_\_ \$25.00 family maximum  
Name of all members of your family attending: \_\_\_\_\_  
Please indicate the ages of your children. \_\_\_\_\_  
(If no age is indicated, we will assume they are over the age of 18). \_\_\_\_\_  
Home Phone \_\_\_\_\_ Cell Phone \_\_\_\_\_ E-mail Address \_\_\_\_\_

**Information about Child Care:** If your children will be attending child care, please indicate their names and ages (available for ages 12 and under). Please indicate whether the child has a bleeding disorder or is a sibling/relative. Childcare will be available from 10:30 a.m. until 3:00 p.m.

Name \_\_\_\_\_ Age \_\_\_\_\_ (circle one) Bleeding Disorder/Sibling/Relative  
Name \_\_\_\_\_ Age \_\_\_\_\_ (circle one) Bleeding Disorder/Sibling/Relative  
Name \_\_\_\_\_ Age \_\_\_\_\_ (circle one) Bleeding Disorder/Sibling/Relative

**Total Meals (indicate number requested):**

Adults \_\_\_\_\_ Saturday Lunch (see choices below) Kids (12 & under) \_\_\_\_\_ Saturday Lunch (Chicken Fingers)  
Adults \_\_\_\_\_ Saturday Dinner Kids (12 & under) \_\_\_\_\_ Saturday Dinner  
Adults \_\_\_\_\_ Sunday Breakfast Kids (12 & under) \_\_\_\_\_ Sunday Breakfast  
For Saturday lunch, adults please choose between  
BBQ Pork Loin Sandwich # \_\_\_\_\_ OR  
Roman Chicken Breast Sandwich # \_\_\_\_\_

**Lodging:** Hemophilia of Iowa will be providing one (1) hotel room per family registration/Hemophilia of Iowa family membership with a maximum of five (5) persons in a room. One (1) rollaway bed will be available upon request. Hemophilia of Iowa will be providing your name to the hotel via a rooming list. You will be asked at check in to indicate what form of payment you wish to use for any incidental expenses. **Rollaway needed: Yes No**

**Mileage:** Hemophilia of Iowa will provide mileage reimbursement for those needing assistance. This will only be for the families with children who have a bleeding disorder or adults who have a bleeding disorder. No one else will be eligible for mileage reimbursement. The mileage reimbursement rate will be \$.14 per mile round trip. Forms will be available at the registration table, and payment will be sent to your home after the meeting. These forms must be turned in at the registration table. No forms will be accepted after the annual meeting has come to a close on Sunday, October 29, 2006.

**Afternoon Sessions:** See the enclosed flier for details on the afternoon sessions. Please indicate below which session you are planning to attend. Families can split up in order to attend multiple sessions. Please note the athletic club will allow children of all ages as long as an adult accompanies children under the age of 12 at all times.

BioBuddies (targeted for children aged 3-10 yrs old) # \_\_\_\_\_  
Aspen Athletic Club (all ages as long as with an adult) # \_\_\_\_\_  
First Step "Parent Information Exchange" (designed for parents with younger children with a bleeding disorder) # \_\_\_\_\_

**Membership Dues and Registration Fee:** Membership dues for 2006 and the Registration Fee are due on or before **October 7, 2006**. If your 2006 membership dues have not been paid, please complete the reverse side of this form as well.

Make check payable to **Hemophilia of Iowa** or use a credit card: (circle one) Visa MasterCard

Card Number: \_\_\_\_\_ Expiration Date: \_\_\_\_\_

Name as it appears on card: \_\_\_\_\_

Address as it appears on card statements: \_\_\_\_\_

Signature of card holder: \_\_\_\_\_

Thank you for choosing to attend the Hemophilia of Iowa Annual Education Weekend. Registration confirmations will be sent out via e-mail; and, if no e-mail address is available, then via the regular mail.

# Hemophilia of Iowa Board Members

## Interim President

Mary McCarthy (9/2005 - 9/2008)  
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Kari Atkinson or  
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hoi\_bloodline@yahoo.com

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Jim Brown (9/2004 - 9/2007)

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jim@mwcornerstone.com  
C: 402-440-2882

Bill Laughlin (9/2005 - 9/2008)

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Riverside, IA 52327  
blaughlin@biorx.net  
C: 888-442-4679

## Test Your Insurance Savvy!

Can you answer the following questions related to your insurance coverage?

1. Does your plan cover all therapy choices? Do you know how much you are paying per unit for your Factor?
2. What will your total out-of-pocket costs be? (Premiums, deductible, co-insurance, co-pays)
3. What is your insurance cap? What are your options after the cap? Is your factor billed as part of major medical or as a pharmacy cost?
4. Are there formulary restrictions? Will you have a choice of Factor?
5. Do you have to get Factor from a designated source or can you choose which pharmacy or Home Health Care you want to work with?
6. Is there a waiting period for pre-existing conditions? Do you have insurance gap coverage?
7. Do you know your reimbursement hot-line number?
8. Have you enrolled in your specific Patient Assistance Program?

Keep in mind that Medicare requires regular re-application!

**Hemophilia of Iowa**  
**Membership Application**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone #: \_\_\_\_\_ Cell #: \_\_\_\_\_ E-mail: \_\_\_\_\_

Please circle the best option for you:

Best time to contact me: AM    PM

I prefer to be reached by:        Mail                    Phone                    E-mail

Would you be willing to serve on a committee?    Yes    No

Would you like to be informed of workshops involving bleeding disorders provided by our various vendors?    Yes    No

Would you like to receive our quarterly newsletter The BloodLine?        Yes    No

**Membership Dues**

**January 1 - December 31, 2006**

**Single \$20.00, Family \$35.00, Industry Representative \$50.00**

**& Friends of Hemophilia of Iowa \$100.00**

Single and Family rates are for those who either have a bleeding disorder or have a relative with a bleeding disorder. A relative would be a sibling, grandparent, aunt, uncle and/or cousin to the person who has a bleeding disorder. If you are over the age of 21, you must have your own membership even if your parents have one. Friends of Hemophilia of Iowa are people who do not have a relative with a bleeding disorder but are support people and friends of those who do have a bleeding disorder. The Industry Representative Membership is for those without a bleeding disorder in their family but would like to join Hemophilia of Iowa.

I would like to make an additional donation of \$\_\_\_\_\_ (this is tax deductible).

Please complete the following information so Hemophilia of Iowa can be of best service to you.

What is your association to the bleeding disorder community?

\_\_\_\_\_ I have a bleeding disorder or my spouse has a bleeding disorder.

\_\_\_\_\_ I am a parent of a child with a bleeding disorder.

\_\_\_\_\_ I am a relative of a person with a bleeding disorder.

\_\_\_\_\_ I am a friend/support person for someone who has a bleeding disorder.

If you are a relative or friend/support person for someone with a bleeding disorder, please list the last name of the person who has the bleeding disorder: \_\_\_\_\_.

If you have a child with a bleeding disorder, Hemophilia of Iowa now has a program called First Step. This program is designed to provide a mentor to families with a child, ages 0-7, who have a bleeding disorder.

Mentors are parents of child(ren) that have a bleeding disorder aged 8 +.

\_\_\_\_\_ I would like to join First Step and have a mentor.

\_\_\_\_\_ I have a child eight (8) years or older and would like to be a mentor.

\_\_\_\_\_ I would like more information before I decide to join. Please call me.

**Please mail this membership application and annual dues (Payable to Hemophilia of Iowa) to:**

**Dawn Humburg, 1002 6<sup>th</sup> Ave SW, Humboldt, IA 50548**

**If you wish to pay via credit card, please fill out the below information: (circle one) Visa or MasterCard**

**Card Number:** \_\_\_\_\_ **Expiration Date:** \_\_\_\_\_

**Name as it appears on card:** \_\_\_\_\_

**Address as it appears on card statements:** \_\_\_\_\_

**Signature of card holder:** \_\_\_\_\_

Mailed by:

UIHC

Hemophilia Treatment Center

200 Hawkins Dr., 2507 JCP

Iowa City, IA 52242